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Disease self-management in patients with moderate COPD: a thematic analysis

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ABSTRACT

Background: Treatment of patients with moderate chronic obstructive pulmonary disease (COPD) is challenged by the low priority of the disease by patients and general practitioners (GPs) affecting the extent of self-management. The aim of this study was to explore (i) attitudes to COPD self-management in patients with moderate COPD, (ii) perceptions of GP commitment to pulmonary rehabilitation in patients with moderate COPD, and (iii) COPD knowledge in patients with moderate COPD.

Methods: The study had a qualitative design using semi-structured interviews to explore the views of 14 patients diagnosed with moderate COPD. We applied strategic sampling to obtain maximum variation and conducted a thematic analysis of the data.

Results: Our main findings were that the degree of COPD self-management was linked to the resources of the informants. Further, the patients experienced that GPs only availed themselves of selected parts of the recommendations for COPD treatment by focusing on medical treatment and smoking cessation rather than physical activity and diet. Many patients lacked knowledge regarding the tolerated level of physical activity and therefore avoided activity increasing their heart rate. Finally, many patients were reluctant to accept the diagnosis because the disease is known to be self-inflicted.

Conclusion: Our study suggests that patients with moderate COPD need more information, especially regarding the positive effects of physical activity. GPs might need to devote more time to the three main elements of COPD treatment, smoking cessation, medical treatment, and physical activity, to promote self-management and a healthier lifestyle in patients with COPD.

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Chronic obstructive pulmonary disease; patients; COPD self-management; general practice; patient-doctor relationship; qualitative research

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is an incurable and usually progressive disease. For patients living with COPD, the challenges are many, going from acceptance of the disease, attempts to change lifestyle and habits, management of medicine, to management of the potential consequences following disease progression [1–6]. One key challenge is the experience of dyspnea preventing an active lifestyle [1–4]. Moreover, patients fear dyspnea and discomfort during physical activity [7–9]. During pulmonary rehabilitation (PR) [8], and life with COPD in general [10,11], patients need support from professionals and peers. Patient support and realistic activity goals enable patients to participate in PR [8]. In recent years, there has been an increased focus on maintaining activity after PR [10–12] and self-management in relation to the disease [13–15].

The research on daily life with COPD has mainly focused on patients with severe or end-stage COPD. Thus, the group of patients with mild to moderate COPD, most commonly handled in primary care, has not been the subject of much research [16–18]. Considering the enhanced efforts of diagnosing patients with COPD at an early stage [19], there is a need to bring the patients with a mild to moderate stage of COPD into focus and explore their perspectives on self-management of the disease. Self-management is defined here as the processes focusing on illness needs, activation of resources, and living with chronic illness [20]. Existing literature on daily life with moderate COPD suggests that patients lack disease knowledge [17,18,21–23]. This knowledge gap might have consequences for the patients [21], including an insufficient understanding of the effect of self-management strategies [17], the importance of treatment and self-management of COPD, and of the long-

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term perspective [18,22]. Further, the access to healthcare and the extent of self-management of COPD is challenged by low priority of COPD [18]. Low priority is seen from the perspectives of both patients and healthcare professionals causing inadequate treatment [23,24]. Research on self-management interventions, focusing on teaching the patients the skills and behavior needed to successfully manage COPD, shows that self-management can successfully reduce dyspnea [25], improve health-related quality of life and reduce hospital admissions [25,26]. However, a review only including primary care patients with COPD found no statistical difference in health-related quality of life [27]. The aim of this study was to explore (i) attitudes to COPD self-management in patients with moderate COPD, (ii) perceptions of GP commitment to PR in patients with moderate COPD, and (iii) COPD knowledge in patients with moderate COPD.

Materials and methods

The study had a qualitative design using semi-structured interviews to address the aim of the study. We used the term informants to reflect the use of interview methodology. Data were generated in February–April 2016 as part of a larger study on COPD treatment.

Participants

The informants were recruited by data extraction from the municipal database 'Sundhedsportalen' (Health Portal) in Copenhagen, Denmark. Data included information on patients with COPD that had been recruited to PR at municipal health centres in 2012–2015. We applied strategic sampling to obtain a maximum variation of the following variables: Patients with COPD with FEV1 at 50–80 pct. of the normal predicted value, sex, age, marital status, cohabitation, occupation, smoking status, activity level, date of PR referral, and PR execution rate. In total, the data extraction included 1549 patients of which 520 had moderate COPD. Unfortunately, the data were incomplete for many patients, leaving only 52 patients with adequate data for our study. All 52 patients were contacted by phone. Based upon these phone calls, 37 patients were excluded for various reasons and 15 patients gave consent to participate in the study (Figure 1). The informants varied on all the existing variables and had either: 1) fully attended PR, 2) partially attended PR, or 3) not attended PR (no-shows).

Data generation

We developed a semi-structured interview guide addressing the issues in the aim of our study (interview guide, Table 1). Each interview could differ in its structure depending on how the informants told their story. Thus, the interviewer became an active part during the interview by deciding what questions to ask, and further, by having an open, attentive approach to encourage informants to elaborate. The interview guide was pilot-tested and revised before and during the study. We added some introductory questions to

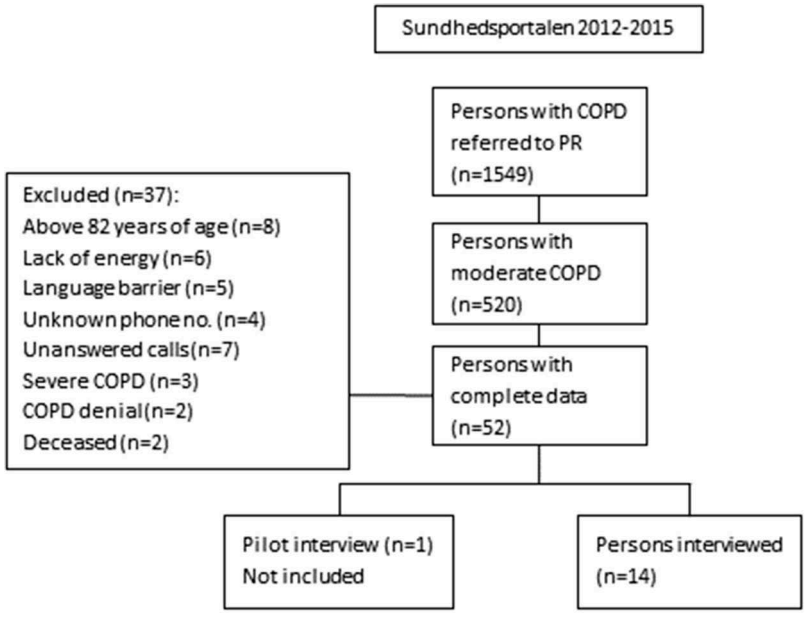

Figure 1. Recruitment flow chart (PR: pulmonary rehabilitation).

Table 1. Interview guide (GP: general practitioner; PR: pulmonary rehabilitation).

Themes in the interview guide	Examples of specific questions
(1) Attitudes toward COPD self-management	How did you discover your COPD? Has COPD changed your life? Would a technological solution improve your self-management of COPD?
(2) Perception of GP commitment to PR	How do you use your GP? How can your GP help you to improve your condition?
(3) Patient knowledge of COPD	Do you know why you have COPD? Do you know how to limit disease progression? Do you have enough knowledge about COPD?

ease the interview. This led to a better starting point for later asking more specific questions. The pilot interview was transcribed and analysed by the first author but was not included in the study. Our position regarding treatment approach of patients with moderate COPD is based on the scientific literature, including our own study of interviews with GPs [28], the concept of self-management [20] and on clinical experience.

All interviews were conducted by the first author (KRM) either in the informants' homes (n = 8) or at a research facility (n = 6) as preferred by the informants. The interviews were audio-recorded and the investigator took field notes immediately after each interview. The interviews were transcribed by two nursing students and validated by the first author.

Data analysis

The interviews were analysed using thematic analysis [29,30]. Investigator triangulation was used as the first and last author discussed each theme. Thematic analysis was applied to identify patterns of meaning and the perspectives, experiences, and attitudes of informants across the interviews relating to the three themes in the interview guide. The method provides a systematic identification of initial patterns and organises the data into representative sub-themes. The analysis was based on two sources of data, transcribed interviews and field notes. The analysis started after the first interview was conducted. The main themes were deductive, according to the themes in the interview guide. The sub-themes were identified inductively as each interview was coded and codes were expanded and collapsed until the themes fell into place. We stopped recruiting patients for interviews when we experienced, through the ongoing analysis of data, that data saturation was achieved [29]. The analysis was supported by computer software NVivo version 11.

Ethics

The study complied with ethical principles for medical research as described in the Helsinki Declaration [31]. The study was approved by the Danish Data Protection Agency (J.no. 2015-41-4462) and The National Committee on Health Research Ethics (ref.no. 15,017,902). The patients were informed of the study verbally and in writing, and written consent was obtained. The informants were informed that the interviews were audio-recorded and that all identifying information would be deleted from the transcripts.

Results

Informant characteristics

We interviewed 14 patients with moderate COPD, 8 women, and 6 men with a mean age of 69 and 65 years, respectively, Table 2. The participants lived in different parts of the city, and most were retired. About half of the informants were active smokers, one had never smoked, and many had comorbidities. Five of the 14 informants had university-level education.

Themes and sub-themes

We identified the following themes:

Theme 1: COPD self-management
1.1 Social gradient in COPD
1.2 Perspectives on the future
Theme 2: GP commitment to pulmonary rehabilitation
2.1 Inadequate pulmonary rehabilitation support
Theme 3: Patient knowledge of COPD
3.1 Disease denial
3.2 Disease acknowledgment

Theme 1: COPD self-management

Social gradient in COPD

The interviews suggested a link between informants' resources and the degree of COPD self-management. A textbook self-management approach was seen in informants with higher education and a good social network. Resourceful informants typically had a history of a physically active lifestyle combined with smoking from a young age. Most of the informants had

Table 2. Demographic characteristics of informants.

	Female n = 8	Male n = 6
Mean age in years (range)	*69 (61–73)*	*65 (51–75)*
Educational level		
High School	-	*2*
College/Vocational School	*4*	*2*
University	*3*	*2*
Missing answer	*1*	-
Employment status		
Employed	-	*2*
Retired	*8*	*2*
Disabled (unemployed)	-	*2*
Marital status		
Single	*3*	*2*
Married	*3*	*3*
Divorced	*1*	*1*
Widowed	*1*	-
Living situation		
Single dwelling	*5*	*4*
Co-habitation	*3*	*2*
Smoking status		
Smoker	*3*	*3*
Ex-smoker	*4*	*3*
Never smoked	*1*	-
Duration of COPD (years)		
1-4	*4*	*2*
5-9	*2*	*1*
10-14	*2*	*2*
15-19	-	-
20-25	-	*1*
Comorbidities		
Yes	*7*	*4*
No	*1*	*2*

successfully quit smoking. Their self-management choices suited their lifestyle and agreed with the recommendations for COPD treatment. Their lifestyle kept symptoms of COPD at bay, which sustained their motivation. One man said:

> *… you might as well face the fact that you don't recover. It just gets worse, actually. But you can delay the disease significantly simply by exercising a lot and not just walking at a walking pace, but really strenuous exercise, where you get your heart rate up and get sweat on your forehead and really get breathless. And of course, also take the medication. (male, 60 years old)*

Informants with fewer resources were mostly physically active but did not associate the benefits of physical activity with COPD. They did not exercise as part of their self-management strategy to alleviate COPD symptoms. Rather, they exercised to keep in shape or keep up with their children. This was reflected in the type of activity they chose, e.g. activities that did not increase their heart rate. They tried to keep their heart rate down to avoid the discomfort of shortness of breath. One woman stressed:

> *But I'm not that good at exercising so the heart rate goes up and I get short of breath. I'd rather avoid that. It's horrible not being able to breathe. (female, 73 years old)*

By contrast, informants with few resources paid less attention to alleviating symptoms of COPD. With a long history of smoking, some were unaccustomed to a physically active lifestyle. These informants focused on other issues in their lives, such as poor economy and comorbidities, and described themselves as incapable of changing their habits on their own, even after the COPD diagnosis. This was also reflected in their inability to quit smoking. Some had tried to quit smoking but were unable to maintain the smoking cessation for longer periods of time. One informant quit smoking but resumed after a major weight gain. He preferred to be '*a slender smoker*' rather than an '*overweight non-smoker*'. These informants were also unable to commit to attending a health and fitness centre for financial reasons. A common finding in less resourceful informants was the perception that COPD was unharmful if daily life was unaffected. One woman said:

> *… it doesn't make me stop doing the things that I've always done. (female, 62 years old)*

Further, a man stressed:

> *I refuse to care for my disease. I don't want to and if it doesn't bother me, I won't bother it. Then it can have its way. My disease doesn't affect me yet, I'm not afraid of it. I need more symptoms before I act. (male, 70 years old)*

Overall, the interviews suggested a connection between the initial response to diagnosis and willingness toward COPD self-management. Some informants had no faith in medical treatment. As such, one woman adhered to the adage: *'If it ain't broke, don't fix it' (female, 68 years old).*

Perspectives on the future

The prospect of sustaining a healthy or unhealthy lifestyle affected the informants' view of the future as hopeful or discouraging. The informants who realized that they were unable to change their habits, were aware that their disease would get worse. Their lives would become more difficult with reduced physical capacity. They dodged the issue and were vague when reflecting on what the future might bring. Some were defensive, describing others' lives as worse, while some were more explicit about their concerns and fears. One informant feared suffocation.

The informants who lived in accordance with the guidelines, however, articulated a realistic view of COPD progression. The thought that their lung

capacity slowly decreases through life was difficult to grasp and made them uncertain about their future. One woman said:

> *If I just knew that the disease did not progress any further, it would be okay to live with. (female, 71 years old)*

Theme 2: GP commitment to pulmonary rehabilitation

Inadequate pulmonary rehabilitation support

The interviews showed that COPD information provided by the GP was experienced as inadequate, particularly regarding COPD self-management. The GP discussed smoking cessation and adherence to medical treatment but did not encourage physical activity and better dietary habits. The informants wanted to know how they could slow down the disease process. Some were instructed to use an inhaler, but none had received comprehensive instruction in COPD self-management. One man stressed:

> *I have been given an inhaler (…) I was told to use it for the rest of my life. So they (GPs) can't help me that much. There is the medication. But otherwise there is not much to do. (male, 51 years old)*

When asked how much the GP talked to them about COPD self-management, one woman said:

> *Uh, not much. And that's why he (GP) sent me on that course (PR). But really you have the feeling that it is the cigarettes. (female, 73 years old)*

One informant explained that she collaborated poorly with her GP regarding her COPD treatment.

She said:

> *I would like to use my GP, but I think we clash because he has an idea that I need a lot of medications, and I have a firm idea that I don't. (female, 68 years old)*

Consequently, medical interventions and smoking cessation were the main elements of treatment offered by the GPs. The resourceful informants consulted a pulmonary specialist and experienced a more comprehensive view of the COPD treatment, including a discussion of medications, diet, smoking, alcohol, and exercise. One informant explained:

> *You take different pulmonary function tests and talk to the doctor about the results afterwards. Also talk a little bit about everything and about exercise and being physically active. This is probably what he (doctor) is most concerned about. (female, 71 years old)*

Patients that consulted pulmonary specialists were left with a better understanding of COPD self-management. A key message was that exercise that increased the heart rate and made them sweat was important.

Theme 3: Patient knowledge of COPD

Disease denial

The interviews showed a variety of responses to receiving the COPD-diagnosis. In some cases, diagnosis was a relief, because 'at least it wasn't cancer'. In other cases, the informants were indifferent because they knew many people with COPD that were more challenged by other conditions. One informant failed to acknowledge his diagnosis because of the disinterested attitude of the GP relaying the message. Many informants were reluctant to accept the diagnosis and argued with the GP. It was important to the informants to put up a fight. One woman described her unwillingness to acknowledge the diagnosis with the expression: 'where there is a will there is a way'. The informants regarded it as a strength to refuse the diagnosis because COPD was for 'losers'.

Many informants had been in denial about their disease and the diagnosis took some adjustment. The diagnosis came as a shock even when the informants had suffered a persistent cough for some time. Some informants even had symptoms of breathing impairment. One woman said:

> *I had pneumonia; I think. Then I went to the doctor (GP) and said I had trouble breathing. He tested me for COPD and after blowing in the tube (spirometer), he said 'You have COPD'. I thought 'It can't be true. I can't have COPD. It's impossible. I can't have COPD'. I thought to myself that the doctors don't get to decide whether or not I have COPD. (female, 73 years old)*

The diagnosis of COPD was generally not a surprise to the informants who were familiar with the consequences of smoking. They were also aware of the link between COPD and symptoms such as coughing and laboured breathing, e.g. expressing that they had felt the symptoms for some time and knew that their smoking habits fitted well with their symptoms. Consequently, they had a clear idea of the situation before the GP diagnosed them. One woman stressed:

> *… When you start to cough a lot, and nothing else is wrong, and you start to have some breathing problems climbing the stairs, then you know you have COPD. I knew. I just didn't want to say it out loud. (woman, 71 years old)*

Disease acknowledgment

Awareness of the increased risk of COPD in smokers led to the acknowledgment of the disease and its

mechanisms. There was mainly an acceptance that the disease was self-inflicted. One said:

> *I was of course sad to hear that I had COPD, but I was not surprised. When you have smoked for so many years, you know that there is a price to pay, for many people at least. (male, 65 years old)*

Disease acknowledgment and insight into the mechanisms of COPD led to a feeling of self-contempt and embarrassment. One woman was reluctant to share her diagnosis with anyone but her husband. She became more open about her disease when her grandson started smoking. Another woman was hesitant toward discussing her disease with her doctor because she was embarrassed. The stigma related to COPD may be the reason that some informants focused on other known causes for COPD than smoking. One man said:

> *"I know that everyone says smoking causes COPD but I don't believe it's the only reason. I think dust at the workplace, pollution from cars and pollution in general causes COPD. Smoking makes it worse, but some people get COPD without ever smoking" (male, 64 years old).*

Alternative explanations for developing COPD included age, lack of physical activity, other diseases such as asthma, work environment, and air pollution. One woman was provoked by the term 'smoker's lung' used by her GP. She needed to find other causes of her disease because she felt stigmatized and said: '*COPD is such a damn looser diagnosis' (woman, 68 years old).*

Discussion

Not surprisingly, our small study suggested a positive relationship between resources (e.g. higher education and stronger social network) and COPD self-management. Moreover, resourceful patients were able to get referrals to pulmonary specialists that were dedicated to helping COPD sufferers. The patients in our study that consulted the GP were dissatisfied with the treatment options available to them, namely that they were limited to medications and smoking cessation rather than PR or self-management. Many patients were ignorant about the type or amount of physical activity that was tolerated in COPD, and they wrongly avoided exercise levels that stimulated the heart rate. Finally, they felt stigmatized because they had acquired a self-inflicted disease.

We will discuss our findings in relation to the concept of self-management, which is a widely recognized component in the treatment of chronic diseases. Self-management is encouraged due to longer life-expectancy, increased incidence of chronic diseases, and limited healthcare resources [32]. The definition of self-management used in our discussion focuses on the activation of patient resources, awareness of patient needs and life with COPD [20].

Regarding the activation of resources in terms of enhancing self-management, our finding that some patients refused to accept their COPD diagnosis might need further investigation. Some patients use defense mechanisms such as denial and projection to avoid confrontation with their disease. One study described four stages of grief after COPD diagnosis: Denial, resistance, sorrow, and acceptance [33]. Although the stages might not appear in chronological order, but rather, interchangeably, it is relevant to consider the patient response to the diagnosis in relation to the therapeutic approach. What could be emphasized here is to take a continuity of care approach [34] with the maintenance of a trusting relationship with the patient. This is recommended to create the best conditions for patients to activate their potential resources, and thus help them to accept their disease and make a collaborative treatment plan. It is important to note that some of the informants in our study with disease denial, actually had good resources and habits to build on. Earlier studies have mainly focused on patients with severe or end-stage COPD [16–18]. Our findings show the importance of acting on COPD at an earlier stage of the disease [19] to enable activation of patient resources.

Regarding life with COPD in terms of self-management, our study showed that the informants struggled with the acceptance of being diagnosed with COPD although they were not surprised. Acceptance-difficulties might be related to the social stigma of COPD as being a self-inflicted disease. Many informants were dissatisfied with the COPD-consultations at the GP. This was also found in a study describing negative experiences such as guilt and self-blame when patients were met by doctors addressing their smoking habits [24]. These negative feelings in patients might promote defensive behavior resulting in refusal to make necessary lifestyle changes [24]. The pattern of communication between patient and doctor or nurse plays a vital role for the quality of self-management of a long-term chronic disease [35].

Our study suggested some knowledge deficits regarding COPD self-management. The informants were not sufficiently instructed in the type and intensity of exercise they should pursue. Some were afraid of increasing their heart rate because it negatively affected their breathing and they feared it would lead to disease exacerbation. Across studies and chronic diseases, patients express a profound need for more information about their disease, treatment, and disease self-

management [24,36–41]. This has also been recognized by GPs that describe the patients' disease knowledge as incomplete [42] and further, that a discrepancy exists in disease perception by patients and GPs [43–45].

Following our discussion and considering the patients' illness needs in terms of improving self-management, another issue in our study was the GPs narrow focus on medication and smoking cessation to the exclusion of other health-promoting activities, experienced by the informants. This finding has been highlighted in other studies where GPs describe COPD treatment as limited to smoking cessation [28] and medical treatment [22,28]. This narrow treatment regime does not meet the recommendations in national and international guidelines that stress the importance of the three main pillars of COPD treatment consisting of smoking cessation, medical treatment, and physical activity [19,46]. Several studies describe under-treatment of COPD [47,48]. Patients need to trust the GPs that have gained responsibility for COPD treatment [49]. Other studies have shown the importance of the role and attitude of the GP in relation to the patients' ability to learn self-management skills [50–52]. Therefore, GPs need to be up-to-date and use the latest knowledge including the clinical recommendations.

Methodological reflections on the study

By assessing the trustworthiness of our study, we need to review the credibility, transferability, dependability, and confirmability. The credibility (true picture) of the findings was strengthened by using an established research method with the execution of empirical method triangulation in the form of transcribed interviews and field notes supported by the computer software system NVivo. As COPD is a progressive disease, and because we did not conduct spirometry prior to interviews, there is a possibility that some of the informants might have developed severe COPD. However, three patients were excluded beforehand for this reason. The transferability (applicability) of qualitative studies is inherently challenged and the informants were a selected group from Copenhagen, all referred to PR, with more than half of the informants completing the PR. This is a selected group as PR attendance is only 10% of patients with COPD in Copenhagen [53]. Further, the extensive exclusion of patients due to missing data is also a limitation. Nonetheless, we were able to conduct a strategic recruitment process with 52 patients. Dependability (consistency) was increased by using the same investigator to conduct all interviews. The confirmability (neutrality) was obtained by investigator triangulation and combining two data sources, interviews, and field notes.

Conclusion

Our study suggests that patients with moderate COPD need more information, especially regarding the positive effects of physical activity. GPs might need to devote more time to the three main elements of COPD treatment, smoking cessation, medical treatment, and physical activity, to promote self-management and a healthier lifestyle in patients with COPD.

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Disclosure statement

The authors declare that they have no conflicts of interest in this work.

Notes on contributors

Katrine Rutkær Molin is doing a PhD on perception of COPD management by general practitioners and patients. She has a broad knowledge in the pulmonary field, both in clinical practice and research.

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